

Crossing the 'bright line' – difficult decisions at the end of life

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ABSTRACT – Patients tell us stories about their lives, their symptoms and their interpretation of them. As physicians we try to make sense of the stories, piecing together the fragments that come our way to discern a diagnosis which we then confirm or refute by examination and investigation. Thus was Samuel Gee's life as a physician: with little in the way of diagnostic tools his 'clinical skills' had to be honed finely and his diagnostic nose well attuned. Perhaps we have today lost some of that clinical intuition. We seek the evidence base for all we do, failing to observe subtleties in our quest for hard science. Following Gee's esteemed lead – for he was celebrated for his clinical descriptions – I will unashamedly use doctor–patient experiences to illustrate my points, particularly around end-of-life decisions.

KEY WORDS: capacity, decisions, dying, euthanasia, palliative

When we address difficult decisions at the end of life, it is worth asking why they are so difficult. Is it because previous decisions have stacked up problems that have only now come to a head? Or is it because our assumptions about ourselves and our roles are being challenged? How do we feel when patients say 'I wish I were dead' or when they refuse our carefully planned treatment in favour of death? In 1991, a GP asked me to see a young dying man, 'D', because all he wanted was a lethal injection. His spinal tumour appeared fungating after failed surgery; he had intractable pain and overwhelming distress. His wife also had to cope with their new baby and two other children. After two hours at his home, I failed to persuade him even to try analgesia. It was only when I admitted a sense of failure that he agreed to try two weeks of hospice care to give his family some relief and during that period, things improved enough for him to accept further input.

When does end of life begin?

For many diseases with a poor prognosis, there are attempts to gain some sort of remission in the inex-

orable progress of the disease. Then, even when the inevitability of death is upon us, there are incidental happenings along the way that can reverse, in the context of an overall picture of a dying person, elements of someone's disease. And then there is the stage of diagnosing dying itself – recognising that the patient is in the *active process of dying* and beyond any prospect of buying more time. Both reversibility and active dying need care in diagnosis. Tools such as the end-of-life care pathway^{1–3} help to make this diagnosis accurately, to ensure that family are informed and prepared and that futile interventions cease, but even the last days can remain an elusive time to predict with complete accuracy.

The care pathway provides anticipatory thinking for smoothing the hours or days of remaining life – for example, subcutaneous delivery ensures that pain or other symptoms do not recur if oral drugs can no longer be swallowed, and discretionary breakthrough doses are available for skilled nurses to anticipate problems like agitation and death rattle and ensure that they are dealt with promptly.

End-of-life is often the end of 'life as it was' for others too. The family may find themselves without the key person, the breadwinner or the strong leader. A parent's death can leave orphaned children to face a harsh and lonely world. Some years ago three young girls, the eldest being seventeen at the time, were caring for their dying mother. They were not in touch with their father and faced being taken into care as their home was being repossessed to pay debts. Flexibility by social services, however, allowed the eldest to become the tenant of a council flat and to be responsible for the two younger children while the local Girls' Day School Trust school they were attending waived the fees. Today they all have careers of their own and are doing well but it could have been very different.

Too often we fail to ask patients at the outset how they want their end-of-life care to be planned (recorded in an advance statement) and whether we can discuss their care with family members.⁴ Too often we leave family members with uncertainties as their world falls apart and the person they love deteriorates. The family need to be considered as 'secondary patients', because they will carry the

morbidity of a traumatic bereavement for years to come. It is the children who carry the greatest damage when excluded. Now young adults, the family of one woman are in turmoil because she chose to hide her cancer from them when they were younger. Treatment was initially successful but, now that she is dying, they are consumed with anger about her secrecy – yet this is not strange when one remembers that children are aware of what is happening even when they are not told. A study of children in Cardiff revealed that the vast majority of parents who had suffered with cancer for a year thought their children were unaware but the vast majority knew everything after overhearing conversations, noticing their parents were upset after the hospital visits and picking up on hushed tones. One child had been told by other children in the playground that his father had HIV when he – and I quote – ‘only had cancer’.⁵

Choices in dying

We now live in a society which presents choices to us at every turn – but what are the choices available to the person who faces deterioration and death? How can they really choose between things they do not want, for the obvious wish is to be better? Are these real choices? Or are they simply the lesser of several feared outcomes? Fear is not indexed in the *Oxford textbook of medicine*,⁶ and in the two volumes of *Principles and practice of geriatric medicine*⁷ the only reference is to fear of dental care. Medicine does not acknowledge those common fears of being a burden, of feeling undignified, of pain and of death itself.

Autonomy is often a byword for choice; they are used interchangeably to indicate that, if a person wants something, he or she should be able to have it. And autonomy is used as the central argument for euthanasia, suggesting that people can dispose of their own lives freely as and when they choose. But in society we are all interlinked – our actions have effects far beyond our self; this was eloquently expounded by Onora O'Neill in describing the concept of principled autonomy.⁸ The effects of our actions may not be felt for many years or may only emerge in bereavement. A husband, who had six extra weeks with his dying wife thanks to a nephrostomy, said ‘six weeks may seem like no time to you, but to us it was a lifetime. We did so much talking’; she prepared him and the children to cope after her death.

Staring deterioration in the face

I was a member of the Select Committee on the 2005 Assisted Dying for the Terminally Ill Bill and as part of that enquiry we took evidence widely. A recurring theme behind requests for euthanasia is an almost unshakeable fear of the future being worse than the present, a fear exacerbated by bad experiences in care, poor symptom control and lack of confidence in the physician.⁹ Such fear of the future is also evident behind many requests for assisted dying in Holland and in Oregon.

Yet poor symptom control is inexcusable. Titrating opioids and avoiding adverse effects should be a core skill of every physician. Sadly, in the wake of Shipman's murders, morphine phobia has returned and some patients are again receiving too little too

late. We may not get symptom control right first time, but failure to seek advice is negligent. The expert armamentarium for pain beyond opioids is substantial and includes an expanding host of co-analgesics, nerve blocks and other practical procedures. Other symptoms such as breathlessness and vomiting, however, deserve as much attention as pain, yet under 0.2% of our cancer research budget goes on palliative care research. How can people expect the relief they deserve when research into essential symptom control and care is so undervalued? Those in palliative medicine, nevertheless, show tenacity in searching for a solution to a problem – one of the most active medical sites on the web is palliativedrugs.com, an international web forum for difficult clinical problems.

Bauby, inflicted by a massive stroke, eloquently illustrated the importance of attention to detail in symptom control. He mused how the sick person's mind takes flight to ‘visit the woman you love, slide down beside her and stroke her still-sleeping face’ but for himself he said ‘for now, I would be the happiest of men if I could just swallow the overflow of saliva endlessly flooding my mouth’.¹⁰

What happens when the physician is faced with a difficult clinical problem, feels a personal failure as the disease has worsened despite all the best efforts, and everyone involved feels ‘battle weary’? It is all too easy to feel defeated and to view death as the solution to the problem. However attractive it may sound, by allowing or indeed expecting doctors to prescribe and possibly administer lethal medication we cross a Rubicon, as we move from doctors being carers during the dying process to becoming the executors of that death, and a new therapeutic option emerges – the option of therapeutic killing.

Currently the law of the land is in complete harmony with medical ethics. If a patient refuses treatment and dies, this is not suicide as everyone has the right to let nature take its course. Nor does the law regard it as killing to discontinue futile treatment when it fails to ameliorate disease. And the law is as clear as medical ethics on the other side of the coin too. If you take any deliberate and intentional action to bring a patient's life to an end, even at their request, that constitutes murder just as much for a doctor as it does for anyone else. The law does not recognise ‘mercy-killing’ any more than does traditional medical ethics. To knowingly give someone the means to end his own life is aiding and abetting suicide; that is illegal, because suicide itself is illegal. Contrary to popular opinion, suicide was not legalised in 1961: it was decriminalised – the difference is important.

The present law represents a ‘bright line’¹¹ – a line which is occasionally crossed, by doctors as well as others, but about which there can be no ambiguity. The overwhelming majority of medical practitioners in Britain were comfortable with this line. In a recent survey of end-of-life decision-making by doctors, Seale reported that they did not feel that the current law inhibited management of dying patients, and he uncovered no covert physician-assisted suicide (PAS) and much less euthanasia than occurs outside the law in those countries that have legalised ‘assisted dying’.¹²

But the ‘bright line’ is under threat. Parliament recently rejected the third Assisted Dying for the Terminally Ill Bill that

sought to legalise this new kind of decision-making by doctors. The decisions involved here go beyond most doctors' competence – such as whether someone who is dying is 'suffering unbearably', whether he really understands what he is doing and whether he is free from internal or external coercion, or distorted thinking. Whether or not you agree with 'assisted dying' (as it is being euphemistically called), there can be no doubt that, if such a law were ever to reach the statute book, it would take medicine across a Rubicon. The 'bright line' between what is ethical and what is not, between what is legal and what is not, would disappear. After the centuries-old precept of 'Do no harm' there would be added the word 'unless...' and killing will have been reclassified as a treatment option. The so-called safeguards in any such legislation cannot be considered safeguards at all if they contain ambiguities capable of broadly different interpretations. The 'bright line' would become blurred, inconsistently applied between one doctor and another and easily crossed without knowing.

Safeguarding patients who ask for death

When the Select Committee examined the proposed safeguards in depth, it found them inadequate in a number of important respects.¹³ The proposals included requirements that the patient is terminally ill, has a prognosis of less than six months, is suffering 'unbearably' due to the underlying condition and has the mental capacity to make the request for assisted suicide.

Predicting prognosis, however, is notoriously inaccurate.¹⁴ My patient 'D' called me in 2001 in a distressed state – his beautiful wife had just been diagnosed with pancreatic cancer. She died after a few months, leaving him the sole parent of their three children – ten years after he himself was given a prognosis of months.

Suffering is a subjective experience, which cannot be assessed objectively by clinical methods, or reliably be attributed to the underlying condition.¹⁵ Cicely Saunders, who founded modern hospice care, was famous for her exposé of total pain as comprising physical pain, greatly enhanced by emotional distress and social and spiritual turmoil, whose origins usually lie far in the patient's personal past.

There is no objective test for capacity – indeed the Mental Capacity Act draft guidance requires that capacity should be assumed unless it can be proven to be impaired. Yet a person can appear to have capacity when their decision making is distorted by fear, depression (undiagnosed in 20–30% of terminally ill patients),¹⁶ or simply misinformation. Coercion in decision making may be real or perceived – and the effect of bad care on a person's sense of dignity and personal worth cannot be underestimated.¹⁷ The sense of being a burden is easy to instil and hard to dispel.

More generally, it is one thing to draft safeguards that make sense to healthy people with everything to live for, but quite another to produce safeguards which will work properly and protect dying people at such a vulnerable time of their lives. The so-called safeguards are illusory; they are procedural tick boxes, not validated objective tests – and it is worth looking back to the

report from Lord Walton's 1994 Committee which found that it is not possible to set secure limits on 'assisted dying'.¹⁸ True informed consent may also be very difficult to achieve, particularly for those under the great physical and emotional stress of illness.¹⁹

But apart from this, why must the patient be dying in order to warrant being released from suffering by death? There are many who suffer terribly; the parents of murdered children, for example, or those who have painful disfiguring, degenerative or psychiatric conditions often feel their attempts at suicide are rational, yet we do all we can to keep them alive and frustrate further attempts. In Holland, some requests for death come from those who are 'tired of life'.²⁰ Lord Joffe, the sponsor of the Assisted Dying for the Terminally Ill Bill, was honest enough in his evidence to the Select Committee to recognise this inconsistency in approach. He said he would prefer that any assisted dying law applied 'to patients who were younger and who were not terminally ill, but who were suffering unbearably'; he saw his second Assisted Dying for the Terminally Ill Bill as 'a first stage' and told the Select Committee that he would welcome extensions of it.²¹ Although he later stated in debate on his third Bill that he had personally changed his mind on this, it is evident that other proponents of euthanasia have not.

And what about those whose request is turned down by an assessing doctor? Will they, as in Oregon, go 'doctor shopping' to find a doctor who will accede to their demand, as happens now with abortion in the UK? In Holland, where 1 in 32 deaths are through euthanasia, the reporting rate stands as 54% – even though it was estimated to be 48% before their legislation encapsulated the moratorium on euthanasia that existed in practice before 1997.²² The Dutch numbers would translate to England and Wales, on a population basis, as 13,000–15,000 deaths per annum – almost one every half an hour on average. This is over four times our road traffic accident rate – a far cry from the 'very few deaths' that proponents of 'assisted dying' predict.

Withdrawing and withholding treatment

The Select Committee looked at this in depth and was not persuaded that there is any ethical inconsistency between the prohibition of assisted dying and allowing the withdrawal of futile treatment.²³ There is a tendency outside medical circles to see this decision point as one of abandonment, of admitting that we can do no more to restore health and just letting the patient die. Yet a decision to discontinue futile treatment also involves a decision to begin end-of-life care. As one relative of a dying patient said to me recently, the negative message as her brother's life support ceased was accompanied by a positive message as good palliative care took over to ensure that he had a peaceful death. For it is the disease that kills the patient and when attempts to ward off death fail, the patient who had been kept alive by our technology is not killed by the doctor.

In evidence to the Select Committee, proponents of euthanasia argued that, as the final outcome was the same (the patient is dead), there is an inconsistency between a doctor withdrawing

life-supporting treatment in the almost-certain knowledge that a patient would die (which is both legal and ethical) and giving a dying patient, at his request, a lethal injection or the means to kill himself (which is not). When faced with stopping treatment, the vast majority of clinicians sincerely wish the patient was not in this situation and would be delighted if the condition turned around and improved – in other words there is a genuine desire against death rather than for it in any withdrawal. Hence, the great majority of doctors who gave evidence to the Committee found the distinction perfectly clear; the intention is not the same, and in both law and ethics intention is very important. The two situations can only be considered as morally the same if there is medical negligence (ie withdrawal or withdrawing of treatment which is available and known to be effective) or if there were an ethical and legal obligation to continue with treatment which has proved futile. There is no such obligation. Healthcare would grind to a halt if there were.

Withdrawing nutrition and hydration is less clear-cut, but the Mental Capacity Act 2005 should clarify this as 'best interest' decisions must take account of a person's known wishes, as recorded in an advance statement or an advance decision document, and as are known by those close to the person. The recent appeal by the General Medical Council and the Department of Health against the original judgment in the *Burke* case is helpful, as the Law clearly states that a person cannot demand intervention.

The practicalities

For PAS, following pre-treatment with an antiemetic such as metoclopramide the patient drinks a massive overdose (9–10 grams) of barbiturate. In Oregon, some patients prefer to crush all the tablets into apple sauce to take them. Whether in liquid or crushed form, however, some patients regurgitate the drug, some die so rapidly (within four minutes) that it seems unlikely that the absorbed drug reached toxic levels in that time and recently a patient woke after three days. In Holland, where such delays in death have encouraged doctors to inject the drugs for a more predictable and rapid effect, the protocol starts with short-acting barbiturate being injected to induce coma followed by the introduction of a muscle relaxant such as curare to stop respiration. Yet even with this method, unpleasant or clinically significant complications are described in the literature.²⁴

For clinical services there are also far-reaching practical implications.²⁵ Do other patients and staff who have a conscientious objection have a right to be shielded from the practice of 'assisted dying'? And will clinical services have a duty to tell all patients how to access it?

Legislators are far removed from the realities of clinical practice. The debates over euthanasia and PAS have continued across the Western world over the last decade, and some reports seem superficial and selective.²⁶ Even the House of Lords report, which gives legislators a comprehensive and balanced overview of the subject, does not deal in detail with the complexities in communication that occur in the doctor–patient relationship.²⁷

The Oregon experience

Oregon's Death with Dignity Act (DWDA) is held up by advocates of PAS as an example of good practice, yet no other US state has rushed to follow Oregon's example. Healthcare in Oregon is funded quite differently to that in the UK. Oregon's health plan of the poor limits funding: it restricts choices of analgesia, and does not provide domiciliary medical and nursing care. It does not fund some life-prolonging treatments, such as for those with cancer who are deemed to have a 5% or less chance of living five years. Oregon will, however, pay 100% of the costs of doctor-assisted suicide.²⁸

According to Oregon's health department, doctors prescribing rates for PAS vary so that in 2005 over half the lethal prescriptions were written by just ten doctors, one of whom wrote eight such prescriptions.²⁹ And each report has the caveat that the figures:

*are based on a reporting system for terminally ill patients who legally receive prescriptions for lethal medications and do not include patients and physicians who may act outside the provision of the DWDA.*²⁶

So in conclusion, where does this leave us?

We do not really know why people die – why does one person die and another live for months or years with apparently the same or a greater disease burden? We do not know how people make decisions and how powerful the influence of the clinician is. The gloomy physician instils gloom, just as the realistic optimist can instil realistic hope. But above all it will be research and education that will improve care and find ways to lessen suffering. Suffering can never be obliterated – it is part of the human condition and yet society must ensure that physicians strive to find better therapies and approaches. In so doing, society protects its most vulnerable and recognises the intrinsic worth of human life. The disability groups are strongly opposed to any moves towards PAS or euthanasia. They feel that disabled people are already viewed as lesser mortals, with their quality of life being judged by others against norms in society that exclude their experiences. Cicely Saunders said to patients, 'You matter because you are you'; she opposed moves to add suicide or killing to the therapeutic armamentarium for sound reasons and out of compassion.

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